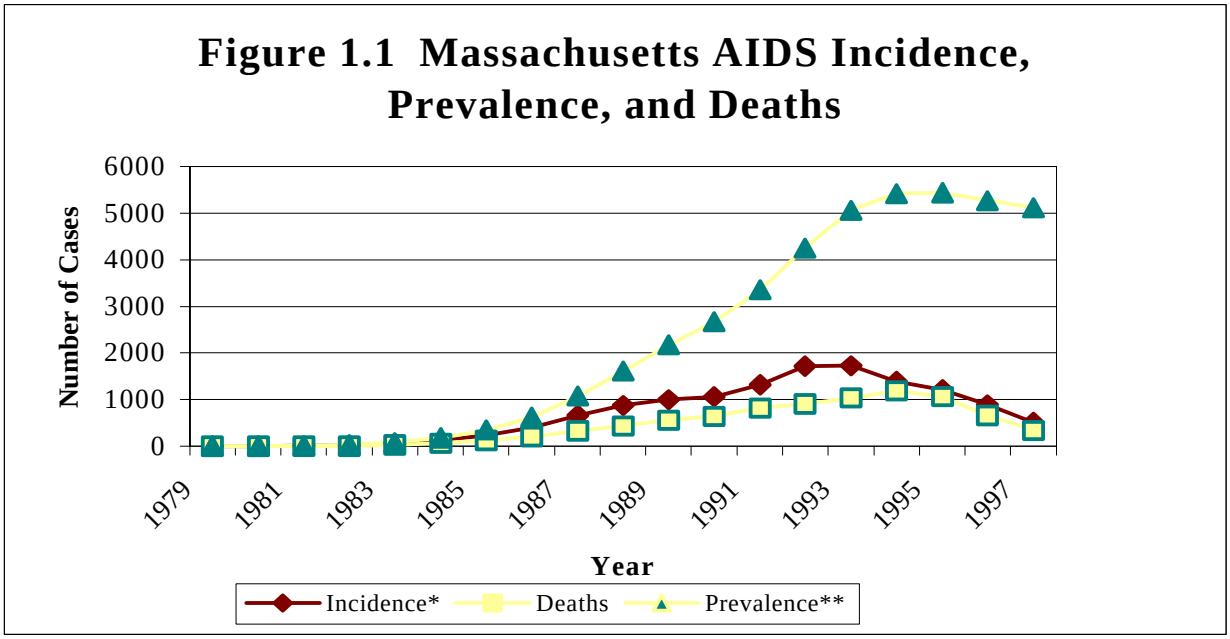
Chapter 1 Introduction

Since 1979, more than 13,342 AIDS cases have been identified in Massachusetts. During the twelve years from 1979 through 1990, an average of 340 cases were diagnosed each year. In the subsequent four years (1991-1994), newly diagnosed AIDS cases averaged 1,538 per year. Since then, the annual incidence has declined to 507 cases.

While some change over time may be the result of reporting patterns, much of the change can be attributed to factors inherent in the epidemic. Early in the epidemic, when less was known about the transmission of HIV and effective medical treatments were non-existent, infection rates increased and more HIV-infected individuals went on to develop full-blown AIDS. When more was learned about HIV and the behaviors involved in its spread, effective prevention strategies reduced the number of new infections, and progress in medical care, postponed the onset of full-blown AIDS in some individuals. These factors resulted in a plateau of new AIDS cases. Since 1994, the advent of new anti-retrovirals and strengthened prevention efforts have contributed to a striking decline in AIDS incidence. This decline is illustrated by the 507 diagnosed cases in 1997, a dramatic drop from the 1,723 cases diagnosed in 1993, even considering the effects of reporting lag and an artificial rise in cases due to the change in case definition in 1993. It is important to note that due to decreases in both new AIDS cases and deaths from HIV-related illness, the number of people living with AIDS[1] remains high. Figure 1.1 shows incidence, deaths and prevalence of AIDS cases in Massachusetts since 1979.

Figure 1.1 Massachusetts AIDS Incidence, Prevalence, and Deaths



*cases of AIDS diagnosed each year
** number of people alive with AIDS each year

[1] Note: In MA HIV infection is not a reportable condition, hence all statewide incidence or prevalence of HIV positive numbers in this report are estimates

This report seeks to address four key questions about current dynamics in the HIV epidemic:

1. Who is at risk for infection with HIV?
2. What are the sociodemographic characteristics of populations at risk?
3. What is the geographic distribution of HIV infection and AIDS cases?
4. What is the impact of HIV/AIDS on these populations?

These questions will be explored through analyses of cumulative and incident AIDS cases; a description of targeted seroprevalence studies; a summary of other risk behavior profiles and community-based HIV risk assessment information; and a discussion of related health and risk behavior indicators. While AIDS case data are the only HIV-related data consistently available on a population basis by gender, race/ethnicity, age, and reported mode of transmission, they don't describe the full spectrum of HIV disease. Therefore, other quantitative and qualitative data on HIV risk will also be employed.

To make data in this report more useful to program planners, the number of transmission categories has been reduced. This has been done by including as *"Other"* both those reported with insufficient information to determine transmission mode as well as all remaining transmission modalities, which in aggregate account for a small part of the epidemic. In addition, individuals engaging in certain behaviors are classified as *"Presumed Heterosexual"* rather than *Unknown* transmission. These changes help to highlight major trends in the epidemic. The transmission modalities used in this report are summarized in Figure 1.2.

Figure 1.2 Explanation of Abbreviations Used to Describe Transmission Modes as used in AIDS Surveillance Figures

Transmission Mode Abbreviation	Description:
MSM	Male to Male Sex
IDU	Injecting Drug Use
MSM/IDU	Male to Male Sex and Injecting Drug Use
HTSX	Heterosexual Intercourse with an individual either known to be HIV-infected or with an individual of unknown HIV serostatus but who has engaged in behavior considered to put them at risk for HIV infection, in lieu of any other reported transmission risk
Pres. HTSX	Individual reported having had heterosexual intercourse with one or more partners, but not with a person known to be "high risk" or with a person known to have HIV infection*, in lieu of any other reported transmission risk
Other	This category includes individuals with no identified risk (NIR), blood component recipients, pediatric cases, and all others.

* CDC classifies these individuals as "No Identified Risk" along with others who have not reported a specific CDC defined risk behavior.

The geographic subdivisions of the state used in this report reflect those used both by the AIDS Bureau and by other Bureaus of the Massachusetts Department of Public Health (MDPH). Massachusetts is divided into 27 Community Health Network Areas (CHNAs) which are aggregated into the six Health Service Regions (HSRs) shown in Figure 1.3. The HSRs are used as the basis for determining regional public health service and funding needs in the Commonwealth.

Figure 1.3 Conversion of CHNAs to HSRs

Health Service Region	CHNA's Included
Western	Community Health Network of Berkshire County; Greater Springfield Community Health Network; Community Health Network of Greater Franklin/North Quabbin; Greater Northampton Area Partnership for Health; Greater Holyoke Area
Central	Fitchburg/Gardner Area; Greater Southbridge; Greater Milford Community Partners for Health; Greater Worcester Area Community Health Network
Northeast	Greater Lawrence Area; Greater Haverhill Area; Beverly/Gloucester Area; North Shore Community Health Network; Greater Lowell Community Health Network; Malden/Medford/Melrose Area
Metro West	Greater Woburn/Concord/Littleton Area; Cambridge Area; Blue Hills Community Health Alliance; Newton/Waltham West Suburban Health Network; Greater Framingham Area
Southeast	Greater Attleboro/Taunton Area; Greater Brockton Community Health Network; Greater Plymouth South Shore Community Partners in Prevention; Cape Cod & the Islands Community Health Network; Greater New Bedford Area; Greater Fall River Area Partners for a Healthier Community
Boston	Alliance for Community Health

The profile itself is organized with respect to populations at greatest risk for HIV in the Commonwealth. The population sections follow a general overview of the state. Whenever possible, the geographic distribution will be described in terms of the six HSRs. All state level analyses of AIDS cases will include all Massachusetts resident cases (including those whose residence at time of diagnosis was a prison, (N=529) reported through July 1, 1998 (N=13,342). Other analyses (i.e. Health Service Region, Standard Metropolitan Statistical Area, N=12,813) exclude prisoners.

Sources and Data Limitations

Bias is a statistical term which describes a systematic error introduced into or inherent in a data set that may affect its interpretation. As described above, several data sets are used to illustrate not only the Massachusetts population diagnosed with AIDS, but also to characterize the nature of risk-taking. All of these data sets share limitations, or have similar types of bias introduced, in that they are reported by third parties, largely providers, who must seek information from the affected individual as to illness, transmission mode, and demographic characteristics. These reports are limited both by the willingness of providers to ask about these factors and that of clients to report on personal behaviors. These data are also limited in their ability to broadly characterize populations. For instance, STD or AIDS case report data can only characterize individuals with STD or AIDS who seek treatment; data on women in prison cannot characterize all women but only those incarcerated women who agree to be tested. Individuals who seek treatment for STD or drug abuse, for instance, may be very different from those individuals who do not. Nevertheless, each of the data sets referred to in this report provide information which adds to our understanding of the relative risk and impact of HIV disease on the people of the Commonwealth. HIV infection is not reportable in Massachusetts and AIDS case surveillance data gives only a partial view of the HIV/AIDS epidemic. Therefore, in order to more fully understand trends in the epidemic, the MDPH supplements AIDS case data with other data. Each data set, and its strengths and limitations are discussed below.

AIDS Case Data: AIDS has been a reportable condition since 1983. All healthcare providers are required by law to report CDC-defined AIDS to the MDPH AIDS Surveillance Program. Reports received directly from health care providers (*routine surveillance)* account for the majority of AIDS cases reported in Massachusetts. The other method of AIDS case retrieval, *active surveillance,* relies on the use of case-finding tools such as database matches, death certificate reviews, and CD4 lab reports which lead to recognizing cases otherwise not reported. This method accounts for a small but growing number of cases. Even though a greater proportion of actual AIDS cases are reported than many other communicable diseases, interpretation of AIDS case data is hampered by a small degree of non-reporting (10%-15%). In addition, not all cases are reported at the time of diagnosis. This phenomenon, known as *reporting lag*, is the difference between the date of diagnosis and the date of report and can lead to some uncertainty. This is especially true with recent data since reporting lag leads to an undercounting of recent cases (prior six months). Changes in the definition of AIDS, which now includes a number of conditions which must be verified by a laboratory test, specifically CD4-based diagnosis, have increased reporting lag. Because confirmatory laboratory results are received by the provider after the patient visit neither the medical provider nor the individual are likely to be present to provide information needed for the reporting form. The increased use of *active surveillance* allows for a reduction in both non-reporting and reporting lag, improving the completeness of reporting.

While the decrease in AIDS cases is a promising trend, it does present some problems in analysis. This is especially true when analyses are done of particular geographic and population subsets by individual year of diagnosis. Therefore, much of the analysis in this report looks at the cohort of individuals believed to be alive at the time of this report. Please note that in compliance with

confidentiality policy, cells that contain data on less than five individuals are not released for geographic localities with a total population of less than 50,000.

Unlinked HIV Seroprevalence Data: HIV seroprevalence studies have been conducted by the MDPH since 1988. These studies provide health officials with information to establish, target and evaluate HIV prevention programs, to identify changes over time in prevalence of HIV in populations considered at high risk for infection, and to help project medical needs and costs due to HIV infection. Serosurvey sites are chosen based on geographic location, the demographic and risk profile of the clinic population, and the ability of the clinic to collect blood and risk information from all clients. Unlinked seroprevalence studies are conducted only in sites where voluntary HIV counseling and testing is available. These studies follow the established CDC guidelines for unlinked HIV seroprevalence studies: the sample is drawn for another purpose (routine diagnostic test); only those demographic and risk information routinely collected during a clinic site from all clients can be included in the study; and all samples are blinded prior to testing by having all personal identifiers removed. Additionally, two percent of all samples are discarded, data categories are collapsed to increase cell size, and no reports are given on categorical cells containing less than five individuals. Data from these studies are generalizable only to the population attending the clinic during a given study period. To reduce bias by repeat visits, each survey has specific exclusion criteria. Figure 1.4 below lists the most recent seroprevalence studies by year and clinic population studied.

Figure 1.4 Unlinked HIV Seroprevalence Studies in Massachusetts

Study Year	Clinic Type/Population
1987-1995	Childbearing Women
1988-present	STD Clinics
1988-1997	Drug Treatment Centers
1990–1992, 1995-present	Correctional Facilities

The Survey of Childbearing Women (SCBW) provides information on the level of HIV infection in women of childbearing age in Massachusetts. In the unlinked SCBW, blood specimens routinely collected from newborns for metabolic screening are tested for antibodies to HIV. Maternal antibodies are passively transferred across the placenta during pregnancy, so the presence of HIV antibodies in a newborn blood specimen actually measures maternal antibody status and is only partially predictive of the child's eventual HIV status. Thus, data from the SCBW provide an estimate of the level of HIV infection among the population of women delivering live children. The SCBW is the broadest based unlinked survey of HIV seroprevalence in women. Consequently, the data are less biased by selection than are those from the other unlinked surveys. The SCBW data represent anonymous sampling of approximately 99% of live births to Massachusetts women. Data are grouped by geographic area. Findings from this study are used both to assess the need for HIV related services among childbearing women and to indicate areas for potential pediatric prevalence by geographic region of the state. Due to the study design, limitations must be placed on the interpretation of the data. Information on the number of women giving birth more than once within a year is not available. Small variations in seroprevalence can be attributed to known changes in the distribution of maternity beds. Federal support for these studies was discontinued in 1995.

Centers offering treatment services for injection drug users (IDUs) are important settings to monitor the HIV epidemic and to evaluate prevention programs for IDUs and for their sexual partners. Three drug treatment centers (DTCs) offering methadone maintenance or methadone detoxification services participated beginning in the unlinked serosurvey from 1998 through 1997. Blood drawn to assess liver function upon client's intake into treatment was tested for HIV antibody after all personal identifiers were removed from the specimen. Data on drug use history are retained, but information on sexual orientation is not routinely collected at these centers. Seroprevalence data from DTC is presented with IDU data in this report.

STD Clinics are important sites for monitoring HIV infection because they serve a population at higher risk. Data from three clinics involved continuously in the survey from 1990 to 1997 are used in this profile. The three clinics are all located in urban areas. Remaining blood drawn for syphilis serology is blinded and tested for HIV antibodies. Data from STD clinics are presented throughout this report for adolescents (under age 25), men having sex with men (MSM), injection drug users (IDU), heterosexuals, and women.

Sexually Transmitted Disease (STD) Data: There is a second source of STD data used in this report. The MDPH Division of STD Prevention collects routine surveillance information from health care providers, who are required by law to report nine STDs, including: syphilis, gonorrhea, chlamydia, and chancroid. Another source of STD information in the state includes selected sero-surveillance reports which are concurrently conducted at STD clinics in the state. Bias is introduced for some STDs, such as chlamydia, where screening of asymptomatic persons is done much more frequently in women than in men. A second source of bias is provider reporting. The personal nature of STD data may affect providers' willingness to report. The STD Division has invested in laboratory reporting as an adjunct to provider reporting to diminish bias. Of course, reports are not received on individuals who do not seek medical care, or when diagnostic testing is not performed.

Counseling and Testing Data: Data are collected at all MDPH-funded counseling and testing (C&T) sites in Massachusetts. These sites see approximately 25% of all counseling and testing activity in Massachusetts. Therefore, analysis of these data may not be generalizable to the entire state. The type of client utilizing a publicly-funded counseling and testing site may not be typical of all clients in the state. C&T uses two different methods for risk behavior data analysis. Most C&T data runs employ a method of "hierarchy of risk" where each client is assigned one risk (the most risky) of risks they acknowledged. The hierarchy is based on the Center for Disease Control and Prevention's (CDC) model and generally follows a descending seroprevalence rate from most risky (sex with person with HIV/AIDS) to the least (no acknowledged risk). Therefore, this method is mutually exclusive. For some data runs, it makes more sense to display all acknowledged risks for each client. For example a chart profiling a specific priority population may display all risks acknowledged by individuals in that population, providing a more detailed picture of risk behaviors. This method is not mutually exclusive.

Substance Abuse Admission Data: Substance abuse treatment admissions are collected on every publicly funded treatment slot in Massachusetts. While these data can be said to be representative

of all those seeking treatment in publicly funded slots, they can not be generalized to all substance users seeking treatment or all substance users in Massachusetts.

Advance Data – Births/Deaths: These reports are prepared by the Massachusetts Department of Public Health, Bureau of Health Statistics and Research with data collected by the Registry of Vital Records and Statistics which receives death certificates and releases information about causes of death, including AIDS. The most current year for the Advance Data sets is 1996.

High School Drop Out Rates: These data are recorded by the Massachusetts Department of Education for communities throughout the Commonwealth. The most current data available are from the 1993-94 school year.

Special Population Serosurveys: The Massachusetts Prevention Planning Group (MPPG) contracted with JSI Research and Training Institute, Inc. (JSI) to conduct HIV prevalence studies in selected target populations as part of their CDC-required HIV prevention needs assessment activities. Between June of 1996 and January of 1998, three separate studies were conducted. The first looked at HIV prevalence among clients of homeless shelters in Worcester and found a seroprevalence rate of 6%. The second study was conducted in Boston with young men who have sex with men in Boston and found a seroprevalence rate of 4%. The last study tested out-of-treatment injection drug users in New Bedford and found a seroprevalence rate of 26%.